

# Overview of SACGHS' Session on Genetic Discrimination

Agnes Masny, R.N., M.P.H., M.S.N.

October 18, 2004

# Genetic Discrimination Task Force Members

- Agnes Masny  
(Chair)
- Cindi Berry
- Barbara Harrison
- Debra Leonard
- Emily Winn-Deen
- Robinsue Frohboese  
(OCR)
- Peter Gray (EEOC)
- Tim Leshan (NIH)
- Paul Miller (EEOC)
- Joann Boughman  
(ASHG)

# Overview

- Evidence of genetic discrimination and the impact of fear of discrimination has been difficult to document
- The lack of “sufficient” evidence of discrimination is cited by opponents of federal nondiscrimination legislation
- In June 2004, the Committee decided to undertake an effort to gather additional perspectives on the impact of genetic discrimination in order to provide the Secretary with additional information that might be useful in addressing this potential obstacle to federal legislation

# Purpose of Session

- To learn more about the magnitude, scope and nature of genetic discrimination throughout society
- To provide the public with a forum to discuss this issue
- To identify next steps in response to the information collected

# Three Panels

- Members of the Public
- Healthcare Providers
- Additional Stakeholders

# Patient Panel

- Panel consists of members of the public who:
  - Have experienced genetic discrimination
  - Have altered health care for fear of genetic discrimination
  - Have paid out of pocket to avoid discrimination

# Provider Panel

- Panel includes providers who have patients who:
  - Have altered healthcare decisions because of the fear of genetic discrimination
  - Have not participated in genetic research because of the fear of genetic discrimination
  - Have expressed concern about genetic discrimination

# Additional Stakeholder Panel

- This panel represents additional perspectives on this issue, including:
  - Legal
  - Employers
  - Health Insurers
  - Society (through town hall meetings conducted by the Center for Genetics and Public Policy)

# Written Public Comments

- The TF requested written public comments through:
  - FR Notice
  - SACGHS Website
  - SACGHS Distribution List
  - ACOG's Website
  - Various listservs

# Written Public Comments

- A total of 43 public comments were received from:
  - Members of the Public (22)
  - Health Care Providers (11)
  - Professional Organizations (9)
  - Representative Louise Slaughter

**Panel 1**  
**Members of the Public**

- Heidi Williams, Cecilia, Kentucky
- Phaedra Malatek, Chicago, Illinois
- Rebecca Fisher, Oakton, Virginia
- Tonia Phillips, Roanoke, Virginia
- Paula Funk, Little Rock, Arkansas
- Maria Carolina Hinstrosa, Washington, DC
- Phil Hardt, Phoenix, Arizona

**Panel 2**  
**Healthcare Providers**

- Jeff Shaw, M.S., Oncology Genetic Counselor, Penrose Cancer Center
- Donald W. Hadley, M.S., Associate Investigator, NHGRI
- Mark Brantly, M.D., Professor of Medicine, University of Florida Health Sciences Center

**Panel 3**  
**Other Stakeholders**

- Kathy Hudson, Ph.D., Center for Genetics and Public Policy
- Jane Massey Licata, J.D., Ph.D., Licata & Tyrell P.C.
- Joanne Armstrong, M.D., M.P.H., America's Health Insurance Plans
- Society for Human Resources Management